

The Good Fight

Parents across the nation - and in our own backyard - are finding support through FightSMA's FighterMom program.

Bland Crowder

Richmond.com

Wednesday, May 30, 2007

Barely two months ago, the **Stone** brothers, **Nicholas**, 9, and **Elliott**, 7, received a devastating diagnosis: myotonic muscular dystrophy.

MMD, the most common form of adult muscular dystrophy, is a genetic disease that causes progressive wasting of the muscles of the face, neck, hands and feet and of the organs, including heart, lungs, digestive system and brain. There is no treatment or cure – yet.

For their parents, **Edibell** and **Todd**, the diagnosis explained a lot. The boys have been in various types of therapy since they were 2 or 3, Edibell said. "Their response to the therapy has been pretty good, but it hasn't been great, and I didn't know why," she said. But with the diagnosis, "now we understand why."

Although crushing, the diagnosis gave the Stones a focus. Research, Edibell said, is the only way out of their situation.

Last year, **Dr. Mani Mahadevan**, a research physician at the University of Virginia, implanted an MMD gene into laboratory mice and with a triggering mechanism was able to toggle the disease off and on in the animals. This breakthrough is a ray of hope for the Stones and the 750,000 people worldwide with MMD.

So Edibell and Todd mobilized to raise money for Mahadevan's studies.

"My strongest connection to people is my friendship," she said. They formed Stone Circle of Friends, through which their friends, acquaintances, colleagues – and those people's friends – have come to take up the Stones' battle and help raise funds, 100 percent of which goes to support Mahadevan's research.

Edibell's cousin designed a logo and their website. Todd produced a video. Edibell wrote the website text and the letter that is the center of their fundraising mailer. And with the help of their circle, they have fundraising events slated through New Year's.

"With the letter alone, we've raised almost \$70,000 in two months," Edibell said. Different circles, such as Todd's fellow lawyers, nearby schools and local musicians, sponsor often innovative fundraisers.

The Stones clearly have a gift. But despite intuition and savvy, they have been inventing their own wheel. Recently, however, Edibell joined with a nationwide network of mothers who provide a support group that will buttress the Stones' battle. Through a West End neighbor, she met **Martha Slay** and became a **FighterMom**.

Martha and **Joe Slay**'s son **Andrew**, now 21, has spinal muscular atrophy, the No. 1 genetic killer of children under 2. Martha and Joe began their fight in 1991, which soon developed into the international nonprofit group **Fight SMA**, based here. Martha is its president.

A program of Fight SMA, FighterMom was originally designed to extend information and support to other parents battling any serious or incurable disease or disorder affecting their child.

"I have this in my hot little hand," Martha said, brandishing the distinctive FighterMom manual that she and Joe, a public relations professional, published. It's a looseleaf binder that, as she puts it, presents "anything that we could possibly share from the past 16 years," such as how to organize and get attention for a disease.

"I can look at the manual and see that what I've done is pretty much how [Martha and Joe] started out," Edibell said. "This is very exciting, because I really had no model."

FighterMom remains an information source for disease advocates, but over Mother's Day weekend, Martha and company launched a new, updated program, answering a big need among families shouldering responsibilities like the Slays' and the Stones' – the need to not feel alone.

"The more moms I meet, the more I see that the overriding urge is for community, for people to connect with one another." Martha said. "People need exercise buddies, for crying out loud! And to have a really severe demand on your life and to feel like you're alone – what is more defeating?"

And like many communities these days, FighterMoms can find theirs on the Internet.

The website, fightasma.org/fightermom, features message boards, the FighterMom Blog, members' blogs and the "Fighting Back" podcasts, in which people – Edibell, for instance – tell their own stories about their fight with their children's diseases. And because they're online, people separated by hundreds, even thousands of miles, needn't be fazed by physical distance.

A FighterMom doesn't even have to have a child with a disease. Some just want to make things easier for people who do. One woman, Martha said, helps navigate the morass of insurance claims, even the smallest of which can sometimes seem daunting. Another might run interference for parents who need a ramp built for a wheelchair or who need to apply for government aid for home modifications for their child.

"Children aren't supposed to have problems," said Martha. "They're supposed to be worried about peanut butter, not about life, not about breathing, or learning or any of the things that you just do because you live. And the fact that there could be these hard barriers, and you can't put the pedal to the floor and run through them – a crisis brings out some coping mechanisms, 'I'm coping with this terrible diagnosis by doing these things.'"

Sharing those things, and providing a community in which others can do the same and explore innovative ways for battling diseases, is what being a FighterMom is all about.

For more information about the FighterMom program, visit fightasma.org/fightermom. For more information about the Stone Circle of Friends, visit stonecircleoffriends.com



Todd Stone

Edibell Stone, mother of Elliott (left), 7, and Nicholas, 9, recently became a Fighter Mom.